Caring Needs of Patients With Rheumatoid Arthritis

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The goal of this study was to identify, through the application of Watson's 10 carative factors, the caring needs specific to the human experience of having rheumatoid arthritis and undergoing acupuncture treatment. The study was conducted at a large university hospital in Stockholm, Sweden. Interviews were conducted during manual acupuncture treatment employing a conversation guide derived from Watson's theory of caring. Six women had 20 sessions each over an 11-week period. A thematic analysis of the resulting 120 audiotaped sessions revealed four predominant themes: seeking help, searching for meaning, uncertainty, and fear of being disappointed. These four phenomena captured the complexities of the physical, emotional, social, and existential experiences of the patients.

For those with a chronic illness, it is vital to be involved in their own care and treatment: to know what effects interventions have, not only in clinical terms but also in terms of the individual's whole life (Benner & Wrubel, 1989). This applies not only to the physical aspects of the patient's care but also to the caring and existential aspects. The treatment of patients with rheumatoid arthritis (RA) has become increasingly technological. For this reason, it is essential to identify the caring needs of these patients so that they may be addressed more consciously within the context of their total care. The aim of this study was to identify, guided by Watson's (1988) 10 carative factors, those caring needs specific to patients with RA who seek acupuncture treatment.

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Background and Review of the Literature

RA

RA is a severe, progressive collagen-vascular disease with an unpredictable course. The effectiveness of long-term treatment is limited and individual. As in many chronic diseases, cure is currently impossible. Thus, interventions are aimed at relieving symptoms and improving functional performance. Literature specific to the care of patients with RA is often confined to medical-surgical interventions. Outcomes are measured by the results of the medical care process rather than by evaluating whether the psychosocial needs of the person have been met. Although persons with RA have reported pain as the most limiting aspect of the disease (Gibson & Clark, 1985; Stenström, Lindell, Swanberg, & Nordemar, 1990), several recent studies suggest that psychosocial factors, such as self-image, relationships, activities of daily living, and finance, are equally important in the determination of functional outcome of these patients (Hagglund, Haley, Reveille, & Alarcon, 1989; Lorish, Abraham, Austin, Bradley, & Alarcon, 1991; Stenström, 1992). The World Health Organization's (WHO) definition of health, as a state of physical, mental, and social well-being, supports the need for the investigation of psychosocial outcomes (Taal, 1993; WHO, 1958).

Watson (1996), for example, has described outcomes as being mainly concerned with death, disease, disability, discomfort, and dissatisfaction. She refers to health as

> unity and harmony within the mind, body, and soul. Health is also associated with the degree of congruence between the self as perceived and the self as experienced. Such a view of health focuses on the entire nature of the individual in his or her physical, social, esthetic, and moral realms—instead of just certain aspects of human behavior and physiology. (Watson, 1988, p. 48)

Acupuncture

Acupuncture is an ancient therapeutic technique of Chinese medicine. It first appeared in approximately 200

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B.C. in one of the earliest comprehensive manuals of medical knowledge (Veith, 1972) and may have derived from the experiences of implanting sharp needle-like objects into the body to relieve local inflammation and alleviate pain.

Experimental evidence of the various biological effects of differing methods of stimulation (Andersson & Holmgren, 1975), as well as beneficial clinical effects of acupuncture in a growing number of disease processes (Ernst & White, 1997), has been demonstrated. Also, as a clinician of acupuncture, one has empirical evidence that significant positive clinical outcomes do exist. Several factors may confound and influence the clinical responses that apparently occur.

Pathophysiological changes underlying clinical conditions (which differentially involve the endogenous pain control system) will determine the response to acupuncture (Moolamanil, 1995). There is also evidence that various qualities of acupuncture stimulation involve different mechanisms of endogenous pain modulation and, therefore, the responses of differentiated pain may relate to those specific qualities (Andersson, 1979; Sjölund & Eriksson, 1979). Finally, it is known that psychological determinants can alter pain perception (Almay, Johansson, Von Knorring, Terenius, & Wahlström, 1978).

Watson's Theory of Caring

Watson's (1988) theory of transpersonal caring, as put forth in her book *Nursing: Human Science and Human Care*, is consistent with the researchers' theoretical and philosophical approach to care. The nurse-acupuncturist used, in a systematic way, a conversation guide derived from this theory to aid in identification of the caring needs of the patients in this study. Watson describes caring as being totally present or "ontologically authentic" in one's approach to the one being cared for. This requires being "intersubjectively" involved with that person. This relationship, referred to as transpersonal caring, allows the common humanness of both the caregiver and the one being cared for to be shared in the mutual ground of the health-illness experience. This reflects Watson's existential-philosophical perspective that clinical practice and research are not only aimed at physical healing but also has aims that are related to individuals' existential values (Watson, 1979, 1988). Watson's caring theory gives structure to the interaction of unfolding of the most basic human qualities to the other person, including the art of being fully present, that is, engaging in treatment with all senses, and to coparticipate in both caring for as well as caring about.

The main components in Watson's theory are 10 "carative factors" (see Table 1). Watson initially described these factors to provide a structured, standardized approach to the "caring" aspects of nursing. This theory has been applied in both clinical practice and nursing research to evaluate the nursing process and has been empirically validated in clinical nursing research investigations (Clayton, 1989; Leners, 1990; Swanson, 1991). Watson's theory is also used in the clinical setting as a way to inform and direct the care activities of the clinician while also accommodating the existential nature of the human-to-human interaction.

Table 1
Watson's Carative Factors

1. Humanistic-altruistic system of values
2. Instilling faith-hope
3. Sensitivity for self and others
4. Helping-trusting human care relationship
5. Expressing positive and negative feelings
6. Creative problem-solving caring process
7. Transpersonal teaching-learning
8. Supportive, protective, and/or corrective mental, physical, social, and spiritual environment
9. Human needs assistance
10. Existential-phenomenological-spiritual forces

Design of Study

A qualitative descriptive design was applied. Watson's carative objectives were used for constructing a semistructured conversational guide (see Table 2).

Selection of Participants

A sample of 6 women, all of whom had previously been diagnosed with RA by a specialist in rheumatology, were recruited to take part in this study through a rehabilitation hospital in Stockholm, Sweden. Inclusion criteria were: RA diagnosed for more than 1 year, between the ages of 17 and 66 years, no acupuncture treatment for the previous 6 months, and a stable medication regime. Demographic and disease-related characteristics varied within the group. The women ranged in age from 32 to 66 years (*Mdn* = 48), education from 7 to 16 years (*Mdn* = 11), and disease duration from 4 to 26 years (*Mdn* = 11). One woman had had previous experience with acupuncture, and 4 participants had taken medication for treatment of their disease. Verbal consent was obtained, and each participant was informed that she could withdraw at any time during the course of the study. Confidentiality was maintained by number-coding each participant's data and not using their name during the tape-recorded sessions. Ethics approval was given by the Regional Research Ethics Committee at the Karolinska Institute in Stockholm, Sweden, where participants were recruited.

Conversation Guide

A conversation guide based on Watson's 10 carative factors was constructed. Each question was derived from one of the specific carative factors, as depicted in Table 2. The questions were directly developed from "Watson's Carative Factors Applied in Clinical Care" (Watson, 1996), which describes the specific nursing actions and objectives that are included in each factor. If necessary, open-ended questions were introduced during the treatment sessions and were meant to guarantee that the critical areas of Watson's theory were reflected.

Data Collection

The nurse-acupuncturist gathered the data during routine manual acupuncture treatment sessions. Semidirected conversations using the afore-

Table 2
Conversation Guide

Carative Objective	Questions That Were Derived
1. Identify values	1. Can you tell me about (a) yourself, (b) your childhood, and (c) your family as you were growing up?
2. Identify hopes and expectations	2. What are your expectations of treatment? How do you see your life in (a) 3 months, (b) 6 months?
3. Identify feelings of comfort with self and others	3. Can you tell me about your present family situation and network?
4. Identify ability to establish helping-trusting relationships	4. How do your close friends and relatives react to your RA?
5. Identify need to express positive and negative feelings	5. Is it most difficult for you to show anger, fear, or sadness? What makes you feel happy? What are your experiences and fears of (a) physical pain and (b) emotional pain?
6. Identify ability to solve problems	6. What is your life occupied with now? What can you do to make yourself feel better?
7. Identify perceptions of illness and goals of treatment	7. What do you think your life would be like now without the disease?
8. Identify awareness of supportive, protective, and corrective mental, physical, societal, and spiritual environmental aspects	8. How do you feel about the changes in your body and its function? What are your hobbies and interests? What gives you excitement in your life? What are (a) stress, (b) comfort, (c) privacy, and (d) safety for you?
9. Identify human needs assistance	9. How was your disease first diagnosed? How does your disease affect your daily life? What previous help have you received from (a) healthcare providers and/or (b) alternative therapy? What do you consider to be a good quality of life?
10. Identify need to find existential-phenomenological-spiritual meaning	10. Are you religious, atheist, or agnostic? Facing the basic issues of your life and death, can you live your life more honestly and be less caught up in trivialities? Do you think life has been unfair or unjust to you?

NOTE: All questions (and direct quotes given as answers in the text) are translated from the original Swedish.

mentioned conversation guide were conducted to enable the women to reflect on their concerns. Over a period of 11 weeks, each woman had 20 acupuncture sessions of 45 minutes duration each given by a nurse-acupuncturist. The 120 sessions were audiotaped for later analysis, resulting in approximately 1,300 minutes of data collected. The recordings were then transcribed verbatim.

Data Analysis: A Thematic Approach

A thematic content analysis similar to Benner's (1994) was used, in which meaningful patterns are considered rather than words or phrases; the interpreter moves back and forth between portions of the text and portions of the analysis in an attempt to understand the participant's experience expressed within the text. The aim was to derive themes or patterns related to Watson's carative factors. The transcriptions were first read and reflected on. Themes were identified through a systematic process of comparing and contrasting each woman's own experience over time and contrasting with the experiences of the other participants. Through the entire data analysis process, the main researcher was aware of his presuppositions and personal knowledge related to pain, disability, and quality of life; therefore, "bracketing" was necessary in order to search for themes that represented the participant's own feelings and experiences. The findings were validated through a review process that included a research team. Through this final review, a general consensus on the characteristics of each thematic unit was reached.

Findings

Of the four predominant themes that emerged from the data, the first was identified as "seeking help." This theme reflects the women's attempts to get an acceptable diagnosis and proper treatment for their symptoms and the day-to-day support that they needed to cope with their disease. The second theme of "searching for meaning" describes each woman's need to find what she perceived as the possible causes of her illness and what it meant for her within the context of her own life and beliefs. Whereas the first two themes are more concrete, based in action, the third and fourth themes, "uncertainty" and "fear of being disappointed," are expressions of emotions and are inextricably linked to the first two themes. This relationship will be expounded on in the discussion, particularly as it relates to what effects the women's uncertain and unpredictable symptoms had on their day-to-day living and their relationships with others. Therefore, the caring needs of women with RA who were receiving acupuncture were identified, through the application of Watson's 10 carative factors, as being in the realms of seeking help, searching for meaning, uncertainty, and fear of being disappointed.

Themes

Seeking Help

A common sequence of events emerged as each woman described her experience. Most reported that their initial symptoms had been mild, vague, and nondisabling and that it had been difficult for them to interpret what was happening to them. Attempting to explain what their symptoms meant, they employed a variety of commonsense explanations, such as "minor trauma" and "overexertion." As symptoms persisted or worsened, however, the credibility of such explanations was lost, and the women sought help from their general practitioners.

For most of the women in the study, the explanation of their general practitioner was not wholly satisfying. One woman quoted her doctor as having

said, "Well, it's arthritis and you must live with it." Another physician said, "I'm sorry, but there is not so much I can do." The dissatisfaction with these responses provoked the women to continue their help-seeking behavior by becoming part of the acupuncture project. To them, it meant "the last chance to find a new treatment"; they were "searching for a professional who [could] provide [them] with choices."

Other help-seeking needs were demonstrated in daily functioning: "I sometimes feel I need help just to survive"; "Where can I get help with shoes and proper clothing which will help me with my pain?" "My family spends the summer on our boat. I can no longer do this due to my disability. Where can I find help for this problem?" Many women sought help through, and from, significant others: "It is difficult to balance how much help I need and how much I dare ask my husband to help me"; "My husband has really had to change his habits"; "I have to get help with taking care of myself. My husband even has to help me get up." One woman whose handicap is not obvious said, "No one can see the pain I have; I cannot even lift one liter of milk. I cannot manage without getting help from people all the time."

Searching for Meaning

Every woman had her own individual theory as to the cause of her illness. Some included aspects of biomedical hypotheses: environmental influences, occupational factors, stress, and autoimmunity. Every account had a personal component to it as well because each woman sought to find how the events in her past may have had a bearing on her illness. One woman, whose symptoms began shortly after childbirth, firmly believed that her illness was due to that stressful event.

The process of searching for meaning often exposed unexpressed grief. As one patient shared during a session,

> I have never before shared with someone, outside the family, my grief for my grandchild's death. He died of sudden infant death [syndrome]. My son found him dead in his bed one morning, 5 years ago. I have felt so much pain in my body since then.

Another women lost her brother suddenly, 5 weeks before treatment started. She shared this experience during the session, saying, "How can life be so unjust? It is unfair that a young man like him should die of a heart attack. I have learned during the sessions that so many feelings are inside my body." She also asked, "Can there be a relation between my grief and my illness?"

Others felt there might be some outside influence on the cause of their disease:

> How can life be so unfair? Why have I got this disease? I don't deserve it. I am an honest, kind person who has never done wrong to anybody. If there is a god, why can't he help me when I ask for that in my prayers?

Others expressed a desire to find resolution: "I want to escape from my pain and disability"; "I have learned that I must take ultimate responsibility for the way I live my life no matter how much guidance and support I get from others"; "When I face the basic issues of my life and death, I feel a longing to live my life more honestly and be less caught up in the trivialities."

Uncertainty

The women described how from one day to the next they would have little or no pain and would be able to move around freely, and then they would be unable to do anything. Three women experienced the same dilemma described in the following quote: "Next week I am invited to a party, but since I don't know what condition I will be in, then I think it's better to say no to the invitation." Long-term planning was deemed impossible because of the unpredictability they experienced. Futures became foreshortened to "getting by, day-to-day." Uncertainty was evident in other statements, such as, "I feel very unsure about my feelings. I need help expressing them and accepting myself" and "I feel uncertain and afraid about getting dependent on others."

Fear of Being Disappointed

In one case, the woman held her doctor partly responsible for her progressive disability, saying, "I blame my doctor for letting it go for months. He should have treated me earlier and also informed me about acupuncture treatment." All 6 women also talked about their fear of being disappointed in the acupuncture treatment. The following words poignantly indicate the fear attached to the individual search for a new treatment of the illness: "I have tried everything that is possible for treatment. Now my last hope is this acupuncture treatment, but at the same time I don't dare to hope anything because I don't want to get disappointed again." This fear was also expressed in these statements: "I have recognized that no matter how close I get to other people, I still face life alone"; "When I get this help from others I feel afraid I will be disappointed"; "If I get sad . . . I don't have anything to look forward to, and then I get depressed and don't feel good at all."

Discussion

Seeking Help

The help-seeking process was mostly historical at the time of data collection. However, during the sessions, every woman in this study referred to, in some way, the part that she had played in actively seeking help. Although the issue of providing information to patients concerning their illness has received considerable attention in nursing literature (Luker & Caress, 1989; Wilson-Barnett & Osbourne, 1983), little attention has been given to the active role that many patients assume in attaining this information for themselves. In this study, the patients not only sought information concerning their disease but demonstrated a force of seeking help that was the hallmark of their treatment. They sought help from the traditional medical establishment, family and friends, religious sources, and their social network. This motivation to be helped can be interpreted as a drive or willingness to survive and as the behav-

ior that ultimately led them to acupuncture. The need for help, however, was much broader than the physical aspects: It also included the emotional, social, and existential needs.

When relating the identified four themes back to Watson's carative factors, it was found that Factor 1 (Humanistic—a heuristic system of values) elicited comments that fell into all four categories. This is not surprising considering the general and pervasive influence that values have on most every aspect of one's life. The carative factors that most often identified the seeking help theme were 3, 4, 6, 8, and 9 (see Table 1). Most of these address, in some way, the physical aspect of coping with the disease, but it was also found that discussion of relationships often elicited this need.

Searching for Meaning

Diagnosis often leads to questions relating to the cause of the illness and its meaning within the life of the person with it. In the process of coping with chronic illness, people seek mechanisms that will help them make sense of their condition. In this attempt, people want to know not only the name of their illness but also its cause (Blaxter, 1983; Bury & Wood, 1979). Williams and Wood (1988) propose a process, termed *narrative reconstruction*, by which individuals experience chronic illness like any other unusual or disturbing event, attempting to make sense of it in terms of their previous life experiences.

Unfortunately, despite considerable biomedical research, the cause of RA is unknown. Each woman in the study was cognizant of this on some level and, in an attempt to make sense of her disease, had considered a variety of factors that she thought might have triggered it. The participants had given this considerable thought by the time they arrived at acupuncture treatment. Some had identified a specific traumatic physical or psychological event, whereas others believed that a certain behavior had caused their disease. Most of them regarded themselves as having difficulties expressing anger or not expressing appropriate grief for certain events. Finally, regardless of the age of the participants, there was a searching for meaning on a metaphysical plane, a questioning of "Why me?" This may have involved a higher power or simply a questioning of fate, depending on the patient's beliefs.

Each participant in the study interpreted the meaning of her disease differently from the others. Although the direct question "What do you think is the cause of your disease?" was never asked, this issue appeared in responses/discussions throughout the sessions. Often provoked by questions relating to existential-phenomenological-spiritual forces (carative factor 10), it was revealed that none of them felt that they were sure what "caused" their disease or what was "meant" by having it. In some way, there will continue to be searching for meaning until the individual accepts that some of the causes of the illness will remain unknown. Other carative factors that elicited this need were 3, 5, and 8 (see Table 1), most often those factors dealing with feelings.

Uncertainty

In chronic illness, differences between feeling well and unwell are subtle, and a great deal of uncertainty exists about whether any real illness exists and what action, if any, should be taken (Hart, 1985). All of the women talked about their relief at having been referred to a specialist. This could be attributed to being given what they viewed as an acceptable name or diagnosis for their symptoms. Recognition and naming of a condition may help to clear the air and reduce uncertainty (Bury & Wood, 1979).

In RA, this relief from uncertainty may be only temporary. Textbooks describe a disease that is extremely variable in clinical presentation and course, characterized by fluctuations in disease activity (Engström-Laurent, 1994). For any chronic illness, the meaning and significance of symptoms are never completely clear (Benner & Wrubel, 1989). Individuals need to decide whether new sensations are symptoms of existing or new illness, a sign of further disease progression, or something of a transient nature, such as the result of too much exercise the day before.

Uncertainty, as a theme, has been identified in patients with RA and has been expressed not only in terms of the disease course but also as it relates to disability, deformity, and dependence on others (Stenström, 1992; Williams & Wood, 1988). The accounts of the women in this study illustrate the variable and unpredictable nature of RA and the wide-ranging effects it has on their daily lives. This uncertainty pervades the entire spectrum of the disease experience and is interrelated with the help-seeking and searching-for-meaning behaviors previously discussed. Consequently, Watson's carative factors that identified these themes are common to some of those in the first two themes: 3, 4, 5, and 7 (see Table 1). Again, these are factors that consistently address feelings and perceptions. The nurse-acupuncturist must be aware of this uncertainty as an ongoing and fluctuating state in patients with RA because it influences both the behaviors and needs.

Fear of Being Disappointed

As has been described in other studies, the perceived inability of traditional medicine to help is a prominent concern of patients suffering with chronic illnesses. In contemporary society, when something goes wrong with one's body, a doctor's help is sought with the expectation that the illness will be treated and cured. Chronic illness can lead to difficulties in the patient-practitioner relationship because the persistence of the disease and its resistance to treatment undermines the image of the technical superiority of the doctor (Hart, 1985). All of the participants in the study had previously received traditional medical intervention, and as their stories unfolded, the disappointment in the perceived failures of their treatments and the medical system in general became apparent.

As the participants entered the acupuncture project, although initially

hopeful of its success, they brought with them the dormant fear that this treatment might also be unsuccessful. As with uncertainty, fear of being disappointed is closely related to seeking help and searching-for-meaning. The women were afraid of being disappointed that their help-seeking would not be successful and that they might not reach an answer in their search for meaning. This theme was evident when addressing many of Watson's factors, particularly 2, 3, 5, 7, 9, and 10 (see Table 1). The expression of this need within so many of the factors demonstrates the breadth of possibility of disappointment that the client might encounter. This fear of being disappointed extended beyond the treatment realm to their private lives. They feared abandonment by family, friends, and society in general, which often led the participant to a general posture of mistrust, skepticism, and anger.

It should be recognized that even though the patient might initially be enthusiastic, if treatment does not meet expectation, the issue of disappointment may arise. This fear, therefore, should be addressed in the initial treatments, even though the patient may not verbalize it.

Conclusion

With the application of Watson's 10 carative factors, four themes related to the caring needs of patients with RA who sought acupuncture were identified. These patients have a strong tendency and need for seeking help, they are searching for meaning within the context of a chronic disease, and they are coping with the uncertainty and fear of being disappointed related to the chronic aspects of the disease. These needs affect and are affected by the physical, emotional, social, and existential events of their lives. Awareness of them by the nurse-acupuncturist will allow him or her to be more cognizant of the caring needs of these patients.

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